

BREAST CANCER  
THE LONG ISLAND BREAST CANCER PROJECT

by Marilyn Goldstein  
Photography by Elizabeth Glasgow

**O**VER THE PAST year, in about 3,200 homes on Long Island, strangers rang women's doorbells, sat down at their kitchen tables and on their living room sofas and began asking some very personal questions. Sometimes they collected house dust. Sometimes they requested soil samples from the backyard. Sometimes they even vacuumed the rug. They wanted to know what the resident ate and what she drank. In each case, the visitors requested blood and urine samples.

Most of the subjects were delighted to cooperate. And, why not? The strangers were investigators trying to garner information that one day might help these women, their daughters and their granddaughters defeat the scourge of breast cancer.

About half of those interviewed in their homes already had the disease, having been diagnosed between August 1, 1996 and July 31, 1997. The rest were cancer-free and had been chosen at random. But they are all part of a ground-breaking \$20 million group of studies called the Long Island Breast Cancer Project. Financed primarily by the National Institutes of Health and the National Institute of Environmental Health Sciences, the project will investigate whether environmental contaminants increase the risk of breast cancer

among women on Long Island, where rates are unexpectedly high.

While 101.5 of 100,000 women living in New York State were diagnosed with breast cancer from 1989 through 1993, in Nassau County the figure was 117.1 per 100,000 and in Suffolk, 110.6 per 100,000. The Long Island project is expected to help determine why.

The project is unique in several aspects, according to Marilie D. Gammon, Ph.D., an epidemiologist with the Columbia University School of Public Health and the chief investigator for the principal study in the project. "First, it was federally mandated," she said. "That's not how most studies come about. Second, it's the only study I know of doing environmental home samples. This will be the first look at something like that." It will also be among the largest studies ever to address environmental risk factors.

The cornerstone investigation, accounting for \$7.2 million, is Gammon's case-controlled study of chemicals in the environment. Blood and urine from a random sample of about 600 cases and 400 controls will be analyzed for the presence of such pesticides as DDT, DDD and chlordane; for PCBs (formerly used in electrical insulators); for PAHs (polycyclic aromatic hydrocarbons found in car exhaust and cigarette

smoke). Self-reports of occupational and residential exposure will also be examined. By comparing the breast cancer cases to the controls, researchers can see if there is any difference in the levels of contaminants between the two groups.

About a dozen related studies are also underway, most on Long Island and some of which piggyback the Columbia investigation. In one study, 1,200 Columbia subjects who have lived in their homes 15 years or longer will be contacted to have their homes measured for levels of electromagnetic exposure. A second piggyback study will investigate the soil, water and dust from the homes of a sample of women who have lived in the same locations 15 years or longer. In a third, using geographic techniques, investigators will attempt to derive an estimate of individual subjects' levels of exposure to the chemicals in question on the basis of where the subjects lived and, perhaps, where they worked. Other studies will look into genetic aspects of the disease, new treatment possibilities and historical issues.

Will this result in definitive answers to questions about breast cancer and the environment? "We'll probably have a pretty good idea . . . about the relationships between DDT and breast cancer," Gammon said, "but there are a lot of new areas we're looking at where we don't have other

studies to compare our results to. What will happen is the Long Island Breast Cancer Project will probably stimulate new research in those areas.”

Five years ago, few people on Long Island would have bet that such a study would exist. Back in 1992, it looked like New York State was washing its hands of the quest to determine why the breast cancer rate among Long Island women, particularly in Nassau County, was inexplicably high.

After a series of studies by the New York State Health Department, officials concluded that the reason for the high rate of breast cancer was the victims themselves: Long Island women had high risk factors that included a large Jewish population, an older population and something *Newsday*, in an editorial, called “high

socioeconomic lifestyle.” In other words, wealthy Long Island women were just eating too much quiche and roast beef.

The next year, the Centers for Disease Control and Prevention, after reviewing existing data, confirmed that personal risk factors explained Nassau County’s high rate of breast cancer.

That may have satisfied health officials and the scientific establishment, but it didn’t satisfy the women of Long Island — particularly those who were not high income, not Jewish and not old. It certainly didn’t satisfy all the Long Island women who were so careful about their diets that wearing anything over a size 8 was considered sinful. And it did not satisfy the black women who were dying from the disease proportionally more often than

their white sisters.

“We believed the study was flawed,” said Fran Kritchek, a founder of 1 in 9: The Long Island Breast Cancer Action Coalition, an education and advocacy group. “The Long Island women believed there were other reasons for their high rate of breast cancer, particularly environmental ones — an area the state didn’t investigate.”

The women already knew of suspicious clusters of breast cancer patients who lived or worked together, clusters that ages, incomes and religious affiliations wouldn’t explain. A Nassau County Department of Health study backed up these suspicions. It found there were 253 cases reported in Bellmore in 1991, while the predictable rate should have been 203. In Wantagh, 221 cases were reported while 181 were predicted, and in Merrick the rate was 242 cases when 205 were expected.

The women knew they drank water from the ground, where fertilizers and other chemicals seeped. The women knew their homes had been built on former potato fields that had been heavily sprayed with pesticides. The women knew Long Islanders were plagued with termites and applying chlordane, a chemical suspected of causing cancer, had once been as common as washing the windows.

So, Long Island women mobilized.

Trained in the rings of Hadassahs and church groups, hardened by the battles of school board politics, buoyed by the women’s movement, highly educated and relentless, the women of Long Island took on the establishment demanding a comprehensive study that looked at environmental as well as other factors.

“The women just exploded,” said



Barbara Balaban, then director of the Adelphi Breast Cancer Hot Line.

“Everyone found a voice.”

Balaban, a founding member of the National Breast Cancer Coalition, said that as far back as 1990, the women began holding conferences and petitioning their legislators. They founded 1 in 9 and other grassroots organizations. They even threatened to conduct their own study. They nagged the press, filed petitions, held rallies, and pushed and pushed. “We just never relented; we just plagued them,” said Kritcheck.

Fortunately, breast cancer is an issue with few political negatives and the women took full advantage of this, Balaban explained. Local politicians from Republican Senator Alfonse D’Amato on the right to Democratic Representative Gary Ackerman on the left and the late Republican State Senator Michael Tully in the center got on board. Ironically, it was a losing candidate that finally wrung the study money from Washington.

As Balaban recalls, Phil Schilero, an aide to Representative Henry Waxman, ran for Congress in the Five Towns area and promised if he won, he would authorize a study of breast cancer and the environment. He lost.

But he returned to work as an aide to Waxman and prevailed on him to introduce the breast cancer study bill. Activist Lyn Dobrin calls Schilero, “a politician who lost the election and kept his campaign promise.”

In June 1993, Congress finally voted for the study and the National Cancer Institute and the National Institute of Environmental Health Sciences were selected to oversee the six-year assault.

The Long Island activists didn’t pat themselves on their backs and return home. They stayed on to see the project through. “That’s another unique aspect of the study — the close community involvement,” said Columbia’s Gammon. Susan Teitelbaum, the study coordinator, added: “We’ve gone way beyond what

most studies usually do. We’ve had the unique interaction with community, and we are in direct communication with the Breast Cancer Network (an umbrella association of community groups).”

The unusual aspects of community involvement include a community liaison who works with the scientists on almost every study in the project.

To reinstate a part of the project that was to be shelved because of lack of funding, the Babylon Breast Cancer Coalition raised money which, according to Babylon Coalition President Debbie Basile, was donated to the Columbia University School of Public Health. That portion of the study will look into how non-invasive cancers become invasive.

In order to insure that as many

*Left: Members of the Research Department of Radiation Oncology at L.I. Jewish Medical Center who are studying the growth of breast cancer cells. In the front row are (left to right)*

*Dr. Eliot Rosen, associate professor of radiation oncology; Dr. Itzhak Goldberg, chairman of the department; Dr. Saijun Fan, assistant professor. Back row (left to right) Renqi Yuan, Jian Wang and Yong Xian Ma, research fellows; Qing Hui Meng, research intern; Whi-Fin Wu, research scientist.*

*Right: Dr. Eliot Rosen studies breast cancer cells transfected with BRCA 1 gene to learn what effect the gene has on the growth of breast cancer cells.*



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women as possible would agree to become part of the study if contacted, the West Islip group developed an effective ad: "Just say yes," advising women that if contacted to be part of the study, they should agree. Other groups helped distribute it.

Elsa Ford, president of the Brentwood/Bayshore group noted that when the community pushed to have more subjects included in the electromagnetic field study, the scientists agreed. But with more subjects to study, there were no longer enough machines for measuring EMF levels. "A number of grassroots people got together and wrote checks," Ford said.

"It's taken a long time for both sides, the scientists and the community, to figure out how we can work together," said Susan Teitelbaum.

"It's the wave of the future. [The community] has a different viewpoint. People who are not scientists don't feel restricted by the logical scientific rules and regulations we have to stick by. I can't say we can act on all their requests, but every once in a while they've come up with an idea we could act on."

Among those community originated ideas is the supplemental study for black women, who die from breast cancer at a higher rate than white women. Scientists will analyze only some of the blood and urine samples and home chemicals of white participants. But, because of their smaller numbers within the total population of Long Island, all the black participants' blood and their home chemistry will be analyzed.

To women like Fran Kritchek, the project is well worth their efforts. "The Long Island Breast Cancer Study Project is one small step for woman-kind in the realm of research, but it's the beginning," she said. "Research for women has been under-funded, and with this study the issue of women's health concerns is finally being addressed on a major scale. I see it as a role model for the rest of the nation in exploring highly-suspected carcinogens in our environment. Research is a very slow process. We hope this study continues until we have answers. And who knows, they may come up with something fantastic."

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See page 89 for a listing of local breast cancer coalitions, support groups and hotlines.

*Members of the Network of Breast Cancer Advocates, a coalition of Long Island groups involved in various aspects of promoting breast cancer awareness, are representative of the women who have worked long and hard to see the Long Island Breast Cancer Project come to fruit*

